Executive Summary

Since the AIDS (acquired immunodeficiency syndrome) epidemic was first identified and case reporting (surveillance) first implemented in the early 1980's, 24,551 Massachusetts residents have been diagnosed and reported with AIDS and/or infected with HIV, the human immunodeficiency virus that causes AIDS. Of these people, 42% (N=10,391) have died; 26% (N=6,306) are reported to be living with HIV infection but have not been diagnosed with AIDS; and 32% (N=7,854) are living with an AIDS diagnosis. Including approximations of Massachusetts residents infected with HIV who do not yet know their status or who have not been reported, there are an estimated 21,000 – 23,000 individuals currently living with HIV infection or AIDS in the Commonwealth. Improved treatment options have extended the average time between HIV infection and the development of AIDS, and also have extended the overall survival of people with HIV/AIDS. Consequently, the need for public health services, health care and preventive services has also increased. Recently established HIV infection reporting requirements are beginning to reveal incident disease information: over 1,000 new HIV infection diagnoses were reported in Massachusetts in 1999 and 2000 and over 900 were reported in 2001 and 2002. These numbers are likely an undercount because people who are HIV positive may have not yet been tested, may have been tested and are not in care, or may be in care but have not yet been reported.

Through this expanded HIV/AIDS epidemiologic profile, the Massachusetts Department of Public Health (MDPH) hopes to improve the capacity of local and statewide partners to plan and deliver HIV prevention, diagnostic, and care services, that will help reduce the number of new infections and improve the well-being of those currently living with the virus. The intended audience for this report includes medical and social service providers, policy makers and advocates, and other people with knowledge about and interest in HIV/AIDS.

Who is currently living with HIV/AIDS? (Chapter 2)

As of July 1, 2003, the majority (83%) of people living with HIV/AIDS are age 35 and above, and the majority (71%) are men. For men living with HIV/AIDS, sexual exposure through male-to-male sex accounts for the largest proportion of reported modes of exposure; for women living with HIV/AIDS, injection drug use accounts for the largest percentage of reported exposure, followed by heterosexual sex as a mode of exposure.

The majority of men living with HIV/AIDS are white (non-Hispanic), while women living with HIV/AIDS are predominantly Black (non-Hispanic) or Hispanic. Sixteen percent of all people living with HIV/AIDS in Massachusetts are non-US born, primarily from the Caribbean (40%) and Sub-Saharan Africa (25%).

The racial/ethnic distribution of people living with HIV/AIDS also varies by Health Service Region (HSR). While over half of the people living with HIV/AIDS in the Metrowest, Northeast and Southeast regions are white, nearly half of the people living

with HIV/AIDS in the Western HSR are Hispanic and 37% of people living with HIV/AIDS in the Boston HSR are Black. The distribution of exposure mode also varies across the state: while male-to-male sex predominates as the exposure mode in the Boston and Metrowest regions, injection drug use predominates in the Western and Central regions.

Who is experiencing differential impact from HIV/AIDS? (Chapter 3)

A measure of the impact of HIV/AIDS on a population, the age-adjusted HIV/AIDS prevalence rate varies substantially by race/ethnicity, highlighting disparate impact across groups. At age-adjusted rates of 1,178 and 995 prevalent HIV/AIDS cases per 100,000, Blacks and Hispanics are impacted at levels 10 and 8 times that of whites (120 per 100,000). Among women living with HIV/AIDS, the disparity is even greater. At age-adjusted rates of 882 and 592 prevalent HIV/AIDS cases per 100,000, Black and Hispanic women are impacted at levels 19 and 13 times that of white women (47 per 100,000). At age-adjusted rates of 1,514 and 1,446 prevalent HIV/AIDS cases per 100,000, Black and Hispanic men are impacted at levels 8 and 7 times that of white men (196 per 100,000).

Who is most at risk of HIV infection? (Chapter 4)

Although HIV diagnosis is not a direct measure of disease incidence and may represent a substantial undercount of true incidence, trends in the distribution of HIV diagnoses are the best available indicator for who is most at risk of HIV infection. The distribution of diagnoses across gender has remained steady from 1999-2002 with women accounting for 30% - 31% and men 69% - 70% of new diagnoses in each of these years. Across race/ethnicity, the distribution has remained fairly steady in the past four years as well – with slight decreases in the proportion of cases among whites and Hispanics (42% to 39% among whites and 25% to 23% among Hispanics) and a slight increase among Blacks (from 30% to 34%).

The largest shifts in the distribution of HIV diagnoses in the past four years have occurred in exposure mode. The proportion of cases with injection drug use as the primary reported exposure mode decreased from 30% in 1999 to 17% in 2002. While caution should be used in the interpretation of this decline, it should also be noted that jurisdictions across the nation have seen a similar decline in HIV incidence among injection drug users. For instance, in New York City, several studies have noted a decrease in HIV incidence among injection drug users. It has been suggested that the decline is due to an interplay of the loss of HIV seropositive persons from the active IDU population through death (also seen in Massachusetts) and reductions in risk behavior among persons continuing to inject drugs which may have led to a decline in HIV infection among new injectors.[1]

[1] Des Jarlais et al. Declining seroprevalence in a very large HIV epidemic: injecting drug users in New York City, 1991-1996. American Journal of Public Health 1998 Dec; 88 (12):1801-1806.

The proportion of HIV diagnoses with male-to-male sex as an exposure mode increased slightly from 28% in 1999 to 31% in 2002. While this proportional increase is very small, recent trends in infectious syphilis among men who have sex with men indicate that behavioral risk for HIV infection may be continuing in this population. From 2000 to 2002, the proportion of total infectious syphilis cases reported that were among MSM increased from 24% to 56% and the number of cases more than tripled (from 34 to 113).

While the number of women living with HIV infection in Massachusetts has risen over time, perinatal transmission rates have dropped dramatically. The percentage of known HIV infection transmitted perinatally among mothers known to be HIV positive who gave birth in Massachusetts has decreased markedly in the past ten years, from 26% (N=32) in 1992 to 0% in 2001. The decrease in transmission rate has been attributed to screening programs for pregnant women and increased use of antiretroviral therapy in pregnant women and their infants. In 2001, 100% of HIV-positive women who knew their status before giving birth received antiretroviral therapy during pregnancy and/or during labor and delivery. This marks an increase from 89% in 1996.

Who is infected but does not yet know it? (Chapter 5)

The U.S. Centers for Disease Control and Prevention (CDC) have recently estimated that about one-quarter of HIV infected persons nationwide do not know they are infected[2]. Previous editions of the Epidemiologic Profile estimated that about one-third of HIV-infected person either did not know they were infected or were not in care. People unaware of their infection are unable to benefit from opportunities for improved health and survival associated with HIV-related care and treatment. People who already have AIDS when HIV infection is diagnosed (or are diagnosed with it in two months or less) represent a population that may have first learned about their HIV status late in the progression of HIV disease; they also likely have been infected for more time prior to learning their HIV status than people who learn their status earlier in the course of infection.

Therefore, a profile of people who are diagnosed with HIV infection and AIDS within two months provides an approximation of people who may be infected without knowing it. Among people diagnosed with HIV infection from 2000-2002, 29% (N=894) already had AIDS (or had it within two months) when they were diagnosed with HIV infection. Among non-US born people diagnosed with HIV infection during this time period, 37% were diagnosed with HIV infection and AIDS within two months, compared to 27% of people born in the US or a US dependency. By exposure mode, the highest proportions of HIV infection and AIDS diagnoses within two months were among presumed heterosexual and heterosexual exposures at 36% and 34%, respectively.

[2] Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. Abstract 11. 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002

How have patterns of AIDS diagnoses changed over time? (Chapter 6)

A profile of annual AIDS diagnoses for the 10-year period of 1993 – 2002 (plus the additional years 1985 and 1990 for historical reference) demonstrates how patterns of AIDS diagnoses have changed over time. While some of these changes may be due to reporting patterns, it also is likely that much of the change can be attributed to factors inherent in the epidemic and the response of the Massachusetts community. For instance, the initial steep rise in AIDS cases reflects the earlier years of the epidemic when less was known about the transmission of HIV, effective medical treatment did not exist, and less time elapsed between HIV infection and an AIDS diagnosis. The decreases in new AIDS diagnoses sustained across more recent years may reflect increased awareness about HIV and the improved prevention of its transmission. Additionally, the introduction of new highly active antiretroviral drugs after 1994 and increased access to them in Massachusetts postponed the onset of AIDS among many individuals, causing a decrease in new diagnoses.

Over time, the demographic distribution of AIDS diagnoses has been shifting. For example, from 1993 to 2002, women accounted for an increased share of AIDS diagnoses (from 22% to 29%). Across race/ethnicity, the proportion of Blacks and Hispanics with AIDS diagnoses increased while the proportion in whites decreased. Regarding exposure mode, prior to 1992, male-to-male sex accounted for the majority of exposures, but in 1992, injection drug use surpassed male-to-male sex and has continued to be the predominant reported risk among people diagnosed with AIDS.

Who is dying with HIV/AIDS and how has this changed over time? ***(Chapter 7)***

After reaching a peak of 1,206 in 1994, deaths among people reported with AIDS declined each year until 1998, when there were 316 deaths. From 1998-2001, the number of deaths among people reported with AIDS remained steady at about 300 deaths in each year, but in 2002 there was a decline to 260 deaths. Beginning in 1999, additional deaths were recorded for people with HIV who had not yet progressed to AIDS. The inclusion on these deaths greatly minimizes the apparent decline in 2002 in part because the number of deaths among people with HIV (non-AIDS) increased slightly over the four-year period. The combined number of deaths among people reported with AIDS and HIV (non-AIDS) fluctuates between 1999 and 2002, with a high of 391 deaths in 2001 and a low of 320 deaths in 2002.

The recent fluctuations in deaths among people reported with HIV/AIDS may indicate that improvements in care and treatment are no longer able to effect the same reductions in HIV/AIDS-related mortality as they once did. Trends in mortality among people with HIV/AIDS reflect shifts in HIV infection and AIDS diagnoses as well as highlight differential survival across groups. Since 1993, females have accounted for an increasing proportion of both cases and deaths. Across race/ethnicity, there has been a decrease over time in the percentage of deaths among whites and an increase among Blacks and Hispanics. Regarding exposure mode, there has been a sustained increase in the proportion of deaths among injection drug users and a decrease in the percentage of deaths among men who have sex with men.

Trends in mortality are mirrored by trends in survival after an AIDS diagnosis. From 1987 to 1997, the proportion of people who died within two years of being diagnosed with AIDS declined from 53% to 10%. Then, from 1998 to 2000, the proportion of people dying within two years of an AIDS diagnosis remained level at 8% to 9%, again indicating the possibility that improvements in care and treatment may no longer be able to maintain reductions in mortality.

What are the patterns of health services utilization of HIV-infected people in Massachusetts? *(Chapter 8)*

For the first time in the Epidemiologic Profile, a chapter is dedicated to describing utilization of publicly funded primary care and non-clinical support services for people living with HIV/AIDS. The Massachusetts Department of Public Health HIV/AIDS Bureau, in conjunction with other agencies, jointly funds and oversees a variety of programs including the HIV/AIDS Drug Assistance Program (HDAP), ACT Now primary care facilities, and Ryan White Care Act and other support services. Based on a chart review of a sample of clients from ACT Now centers in 1999 and 2000, high levels of anti-retroviral therapy, medication adherence support and viral load monitoring are being provided, but many consumers are not receiving optimal levels of screening for Tuberculosis, Hepatitis B or Hepatitis C. In a needs assessment conducted in Spring 2003 of consumers of non-clinical and other support services, interviews with 466 individuals living with HIV/AIDS revealed that many have complicated health problems including high rates of Hepatitis C and other chronic and acute illnesses. Most of these consumers are receiving appropriate levels of medical care and have case managers; however additional needs for dental care and mental health counseling were identified. In addition, many consumers reported that their providers do not talk to them about domestic violence, counseling at-risk partners, safer drug use or substance abuse treatment, all of which are important components to comprehensive care for people living with HIV/AIDS. These data will be useful for planning prevention services, as well as clinical and non-clinical support services for people living with HIV/AIDS.

Conclusion

The data presented in the 2004 edition of the Massachusetts HIV/AIDS Epidemiologic Profile show that progress has been made in preventing the spread of the HIV epidemic and improving the health of people living with HIV/AIDS in the Commonwealth. Perinatal HIV infection has dropped to 0%, and declines in AIDS incidence show the success in delaying severe disease. Dramatic reductions in AIDS deaths up to the late 1990's show the impact of wide and early access to highly active antriretroviral drugs in Massachusetts.

However, other indicators show that there is much work yet to be done. A recent plateau in the number of HIV/AIDS deaths may signal that the development of more effective drugs and expanded access to them will be needed to increase survival. Systematic disparities persist among people living with HIV/AIDS who are of different races and ethnicities, living in different parts of the state and born in different countries.

Additionally, many people who are infected with HIV may be unaware of their status or first learn they are HIV positive late in the course of their disease. From 2000 to 2002, 29% of people diagnosed with HIV infection in Massachusetts already had AIDS (or had it within two months), showing the need to improve efforts to provide HIV counseling and testing to people at risk for HIV infection. While these challenges are great, previous successes in Massachusetts show there is a highly skilled, dedicated and mobilized provider and consumer community poised to respond to emerging trends in the epidemic.